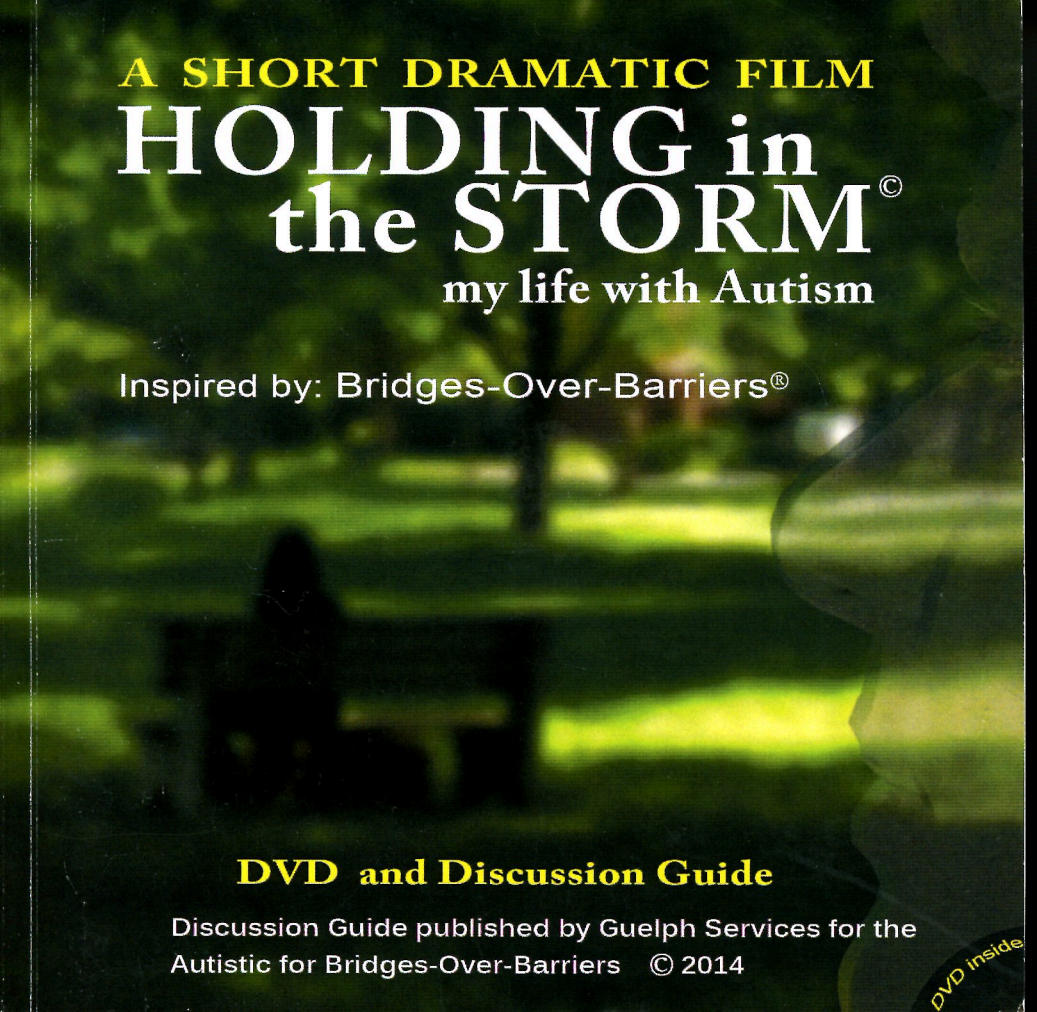
A SHORT DRAMATIC FILM

HOLDING in the STORM©

my life with Autism

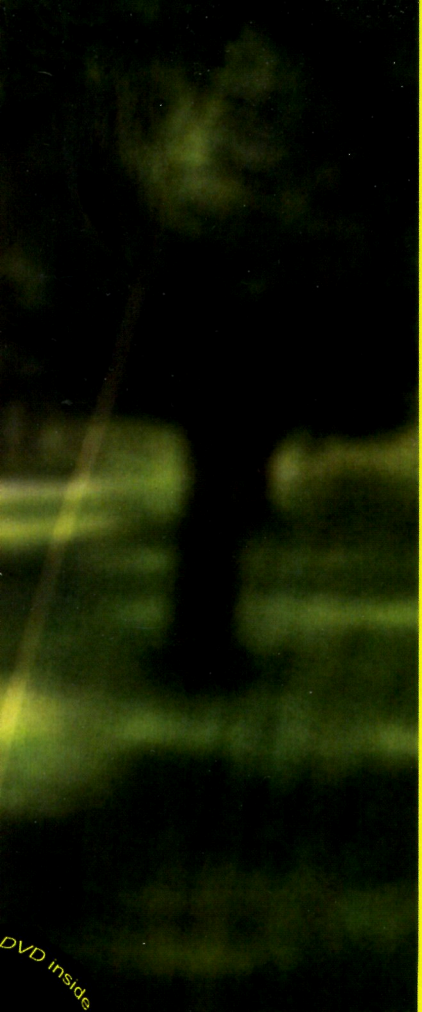
Inspired by: Bridges-Over-Barriers®



DVD and Discussion Guide

Discussion Guide published by Guelph Services for the Autistic for Bridges-Over-Barriers © 2014

DVD inside



'When I communicate with my Bridges group, I feel like we've always been together and that we have a connection deeper than family. I guess we are in fact a type of family sharing the common bond of silence in a world that is seldom silent.'

Kevin Vasey

HOLDING IN THE STORM: MY LIFE WITH AUTISM

Discussion Guide

Elizabeth Bloomfield with Andrew Bloomfield

Guelph Services for the Autistic for
Bridges-Over-Barriers®

First published in 2014 by Caribou Imprints
for Guelph Services for the Autistic and
Bridges-Over-Barriers®
16 Caribou Crescent,
Guelph, Ontario, Canada, N1E 1C9
Email: gbloomfi@uoguelph.ca

Elizabeth Bloomfield, author and editor
Andrew Bloomfield, author of several sections
Copyright © Guelph Services for the Autistic 2014
ISBN: 978-0-9866586-6-2

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, except for brief quotations for purposes of review, without the prior permission of the publisher.

People diagnosed with Autism Spectrum Disorder have been predominantly male though this assumption is now questioned. Please note that general references to male persons with the pronouns "he", "his" and "him" are usually intended to apply to female persons as well.

Cover design by Christine Zorn
Printed by M&T Printing, Guelph

Contents

Foreword by Andrew Bloomfield	5
What is Autism Spectrum Disorder?	7
Why are more people identified with ASD now?	9
Adults as well as children have Autism	12
How many Ontario people live with Autism?	13
How is Autism experienced in adulthood?	15
Gender in Autism	16
How typical is Matthew of others with ASD?	17
What makes Matthew feel he is in a storm?	22
How is Matthew able to hold in the storm?	23
Matthew's "thought voice" and facial expressions	25
How Matthew communicates	27
What we all yearn for: really good support to communicate	29
An autistic poet?	30
Bridges-Over-Barriers® by Andrew Bloomfield	32
Community relationships: awareness -> inclusion: safety, role of a dog, paid work, how to be a friend	35
Towards better lives and more secure futures	40
Learning more about Autism Spectrum Disorder	44
More questions: Holding in the Storm Blog	48

I read the news,
that in this world
we fear....
the homeless,
the depressed,
the different.
I am here and I am different:
No need to fear me.

Our friends are the people who can be with us
and not get upset;
they help us to be who we are
and not what people think we are .

My friends accept the way I am...

I like calm focused friends who listen to me....

My friends take time to know me....

Foreword

The film ***Holding in the Storm*** is inspired by our Bridges-Over-Barriers communicators who have been meeting monthly in Guelph since January 2004. As we cannot speak with our voices, we type our words on various kinds of keyboards. In 2010 our group brought out a documentary film on DVD and a book, both titled ***In Our Own Words***. We challenge stereotypes that people may have about severe Autism and show how important it is to listen to us.

Christine Zorn who made that film with us was so moved by the experience that she and Deirdre Lindsay had the idea of making a dramatic film to reach a larger audience. We Bridges members gave permission for our words to be used. The film was shot in Guelph during 2013 and launched on 29 March 2014 to herald World Autism Awareness Day. Thanks to directors, crew and cast!

The film should help people to understand what it is like to live with Autism as adults and to accept those of us who are different. We are different from "neurotypical" people and also different from one another. But we also share the hopes and dreams of everyone else. This Discussion Guide is offered as an aid to reflect on the meanings of the film and to stimulate ideas of ways that people with Autism Spectrum Disorder (or other differences) can be better included in our communities.

MY LIFE WITH AUTISM

We have imagined questions that the film may suggest to viewers. This guide provides some answers in an overview of what it's like to be an adult with Autism. These are not the last word. We hope that people will continue to think about the film and ask questions. To facilitate this, we have begun a blog at http://holdinginthestorm.blogspot.ca Please visit often and join in the discussion. You might consider hosting a group gathering to view the film and discuss its meanings.

Thanks to Waterloo-Wellington Autism Services and the United Way Guelph Wellington Dufferin for major grants towards producing this film. Donations have also been received from the Linamar Corporation and various individuals to help with completing and distributing the film and guide, hosting the launch events, and maintaining discussion. Guelph Services for the Autistic has sponsored and shelters the project.

We who live with Autism need our friends so much! We dedicate our film and guide to all the people who are our friends. Among these, we especially honour the lifetime community service of Mary A. Johnston of Waterloo and John A. Verhart of Guelph. They have been our friends in so many ways in the past 20 years, and very generous to GSA, Bridges-Over-Barriers and this film project.

Andrew Bloomfield for Bridges-Over-Barriers
Guelph, January 2014

HOLDING IN THE STORM

What is Autism Spectrum Disorder?

The neurodevelopmental disorder we call Autism was identified separately in 1943 by two Austrian-born psychiatrists, Leo Kanner in Baltimore and Hans Asperger in Vienna. Because the children they treated seemed indifferent to other people, the term Autism was used, from the Greek *autos* for self. Asperger's work was little known in the English-speaking world until the 1990s, when the term Asperger's Syndrome began to be applied to milder forms of Autism, especially in people whose communication abilities were less affected.

Autism is a complex and still mysterious disorder or condition, despite a great deal of research in the past 15 years. There is no single cause and no simple cure and people who live with Autism may have unique clusters of symptoms. For many years, Autism was diagnosed on the basis of behaviours that were observed to be different from those of normal children and psychologists and psychiatrists were responsible for diagnosis and treatment. Now Autism is considered more in the realm of neurologists though many specialist insights are needed to understand its complexities. The roles of nature and nurture, genes and the environment, continue to be debated. Both are probably involved, with affected people having a genetic (or epigenetic) susceptibility that may be triggered by environmental factors.

An explanation of Autism as a whole-body accumulation of symptoms is proposed by the pediatric neurologist Martha Herbert: *"Genes and environment interact in the fetus or young child, changing cellular function all over the body, which then affects tissue and metabolism in many vulnerable organs. The interaction of this collection of troubles leads to altered sensory processing and impaired coordination in the brain. A brain with such problems produces the abnormal behaviors that we call autism."* Quoted by Jill Neimark, ***Discovery Magazine*** April 2007. Martha Herbert, ***The Autism Revolution***, Harvard, 2012.

Whole-body strategies have been known to reverse Autism in some children when started early. Adults can be helped to cope with pain and agitation when specific symptoms are eased. But adults with the full range of whole-body symptoms continue to live with severe Autism.

In 2013, a new Fifth Edition of the ***Diagnostic and Statistical Manual of Mental Disorders (*DSM-5)** was published, in which most forms of Autism (including Asperger's) are folded into "Autism Spectrum Disorder" (ASD). The criteria for diagnosis were changed from those in DSM-4 (1994) and its revised version (2000). It is thought that about one fifth of the people being diagnosed with some form of Autism in 2008 would not qualify for ASD from 2013 with the new criteria. But that still means one in every 100 people is on the Autism spectrum.

Why are more people identified with ASD now?

Probably there always were people who combined the symptoms of abnormal social interaction and communication with a strong attachment to their own interests and patterns of behaviour. But in the past such people, if seriously affected, would have been generally grouped in the broad categories of mentally defective, subnormal or mentally ill. Those more mildly affected might have been thought eccentric or loners while a few may have excelled in particular abilities.

Research in the 1960s in various world regions found a constant ratio of 4.5 children in every 10,000 with "classic" Autism as defined by Kanner. This rate grew dramatically from the early 1990s. By 2012, in some regions and localities, even higher rates were found --such as one in every 88 children. By 2014, there is general agreement on a rate of 100 in every 10,000, a 20-fold increase compared with the 1960s.

One factor is the widened definition of Autism. To be identified with "classic" Autism or Kanner syndrome in the 1960s and 1970s, a child had to show clear evidence of communication and social deficits as well as bizarre behaviours. By the end of the 20th century, an ASD diagnosis could depend on a smaller number of criteria. This tendency paralleled the inclusion of people with less severe characteristics and labelled with Asperger Syndrome from the early 1990s as well as people who

combine Autism with other conditions. The trend was somewhat reversed in 2013 with the new official definition of "Autism Spectrum Disorder" (ASD).

A second reason is the increased awareness of Autism and ASD among professionals who make diagnoses and those who plan and provide services. This had a ratchet effect. As increasing numbers with ASD demand more services, perception of available services may encourage professionals to diagnose that condition more often, and so on.

Has there been a real increase in Autism in the past 30 years? This raises many other questions about the causes of Autism. Substantial research shows a polygenetic aspect, various genes interacting to predispose some people to ASD. But while some distinctive features, such as deletions or mutations of genes, have been found in the genomes of some individuals with Autism, it has not been possible to identify one or a few genes that are clearly responsible for all or most cases.

The explosion of diagnoses in the past 20 years has moved some to blame a vast array of new environmental conditions and contaminants. It has been suggested that people with ASD may be particularly sensitive, even genetically predisposed, to environmental irritants. They have been compared to "canaries in a coal mine" in giving early warning of environmental hazards that could affect everyone.

HOLDING IN THE STORM

Failure to find a common cause for all cases has led to understanding ASD as a complex disorder--not a single condition but a group of several distinct conditions that may present a wide range of broadly similar behaviours in people who are affected. So some people prefer the plural terms "autisms" or "Autism Spectrum Disorders".

People with ASD vary enormously in the range and severity of their symptoms but may be thought to share some traits which distinguish them from "neurotypical" people. Most are awkward in social communication and interactions. Many, apparently trying to find and impose order in their environments, insist on patterns, rituals and routines that make sense to them. Oliver Sacks has called this a "rage for order". In some people, such traits may become remarkable abilities and confer an "autism advantage". From some points of view, people with ASD may be considered on a kind of continuum with neurotypical people at large, ranging from empathizers at one end to systemizers at the other, each with his own gifts and strengths.

Some people with ASD have sometimes been distinguished as "high functioning" if they speak and may also have been diagnosed with Aspergers. However such people may be quite challenged in their social and adaptive skills. On the other hand, people who do not speak have long been assumed to have low intelligence and to be "low-functioning" and incapable of language and literacy.

Adults as well as children have Autism

Everyone knows there are children with Autism, but adults on the Autism spectrum are often overlooked. Parents of young children have been very effective in speaking up for their families in the past 20 years, so there are now relatively good resources for preschool and school children. Parents of older adults actually diagnosed as children with Autism may have had little encouragement to advocate or hope. Too many of today's adults with ASD were not diagnosed at all as children. Charities find it easier to appeal to governments, donors and the general public for the needs of youngsters. Now the larger numbers diagnosed as children are aging out of school programs into what can seem a service void.

As far as the research can tell, the same proportions of adults live with ASD as in the child population. Major studies in the United Kingdom since 2006 have found that the prevalence of the symptoms of Autism is the same among adults as among children—at least one in every hundred. But most of those adults had not been formally diagnosed.

Only a tiny proportion of adults with ASD have appropriate supports to lead good and fulfilling lives in their communities. Most suffer from assumptions that they have low intelligence and potential. Too many live restricted lives and have few resources to continue learning.

How many Ontario people live with Autism?

Applying the one-per-cent prevalence to Ontario, there could be more than 135,000 people with the symptoms of Autism Spectrum Disorder.

Using 2011 census data of age-groups, that ratio would mean:
30,500 children and youth from birth to 19 years,
33,125 adults aged 20-39,
38,500 aged 40-59,
21,260 aged 60-79, and
5,178 aged 80 and older.

Based on this rate of prevalence, children and youth make up less than one quarter of the total numbers of people living with ASD in Ontario and there would be over 100,000 adults.

Identifying all those adults is difficult. Large numbers are uncounted and unrecognized because their Autism was never diagnosed in childhood when their symptoms would have been clearer. This is true especially for those over 30 now. As Autism had a very low profile with few services in the past, there was no reason for their families to seek that diagnosis. Professionals and policy-makers may then have classified them as mentally retarded, uneducable or developmentally disabled. It may have seemed futile to try to draw out their abilities.

Some factors may alter the ASD ratio as adults age. Other health conditions may shorten their lives, more than for other adults. Epilepsy for example affects at least one in three with ASD. People with ASD may also be more vulnerable to accidents and to abuse.

Adults with ASD may have lower standards of general health care than other adults. It is hard for many to make their needs well understood and they are often assumed to be incompetent. They may not really understand that anything is wrong and those who do not speak reliably cannot clearly describe their symptoms.

Before they reach adult years, some children originally diagnosed with Autism may improve their social and other skills to the point where they can fully participate in mainstream education and social events. Their families may decide to conceal the original diagnosis of Autism as they feel it to be a stigma.

Our film is part of a movement to think more positively about people who are different. We have tended to assume that those with Autism, especially if they do not speak, have no abilities or intelligence and even that they wilfully obstruct the efforts of their carers and professionals. We think it is more productive to "presume competence" and assume that a person has intellectual and other abilities and wants to learn and to express his essential self in the world.

HOLDING IN THE STORM

How is Autism experienced in adulthood?

"Youth and adults with autism spectrum disorders and co-existing mental health or medical needs are among the most marginalized people in Ontario's health and social service system." This was the conclusion of a detailed survey of 480 Ontarians between the ages of 16 and 66 who actually had a formal diagnosis of some condition on the Autism spectrum. (***Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems***, Redpath Centre, 2013).

The survey found that "Ontario youth and adults with ASD often lead lonely, impoverished lives and struggle to find appropriate health and social supports. Most continue to rely on their families, who suffer in silence because they feel defeated and disempowered by provincial health and social service systems that have abandoned them."

Adults with ASD have a range of abilities and interests. Some, when encouraged, show their potential and prove that support is worthwhile. We hope that viewers will pick up this message in our film. However, the realities of life with ASD for most adults are much harder. The focus may too often be on "what's wrong?" rather than on "what helps to make a good life?" Too many adults experience extreme anxiety, depression, and repetitive or disturbing behaviour including self-harm.

Gender in Autism

The film's lead character is a young man. What about girls and women? Don't they have Autism? In the first counts of children with Autism, the disorder was 3 to 4 times more common in boys than girls. So out of the 4.5 per 10,000 counted in the 1960s, only one would be a girl. When Asperger Syndrome was recognized from the 1990s, only one in ten was a female.

Some outstanding women with Autism have given us valuable insights into their lives. Books by or about Temple Grandin, Donna Williams, Jessica Park, Liane Holliday Willey , Wendy Lawson, Lucy Blackman, Sue Rubin, Dawn Prince-Hughes and Rudy Simone are well worth reading.

It is now thought that girls and women with ASD have been seriously undercounted. Diagnostic criteria and practices were historically biased towards the conventional male presentation of ASD and unreliable for identifying females who may also be able to carry higher levels of genetic mutations without getting any brain development disorders, a "female protective effect." Girls with ASD tend to be less disruptive than boys with ASD. They have more vivid imaginations than boys and usually share more interests with other girls. Girls and women may have been better at adapting to or compensating for symptoms of ASD ("the camouflage hypothesis").

How typical is Matthew of others with Autism?

Our film character is a composite of traits of several members of the Bridges-Over-Barriers group that inspired this film: he is not modelled on a single person.

Each adult with ASD is an individual with a unique combination of traits and symptoms. In a gathering of people with ASD, the differences among them are clearer than the similarities. By the time someone is an adult, the symptoms of ASD may be influenced by each person's life experiences, producing more diversity.

The Bridges members who inspired the film have collectively most of the possible symptoms and complications of severe whole-body Autism. All body systems can be affected—including brain functions, movement, speech, the gastrointestinal system, sensory and self-regulation systems and sleep. They may have allergies to and intolerances of foods and medications, as well as gastrointestinal and respiratory diseases, sleep and eating disorders. Some combine other neurological disorders with Autism. More than one in three adults living with Autism also has epilepsy. Others may also have Cerebral Palsy and Down syndrome. Some are impaired in vision and/or hearing. Adults with Autism can have issues of mental health such as anxiety and depression. Living with these challenges can be exceedingly frustrating and painful. What is

most impressive is the courage and determination to get around and over the obstacles.

Most Bridges members experience hypersensitivity to stimuli affecting any or all their senses—not just the five basic senses of sight, smell, sound, taste and touch but also the proprioceptive (sense of relative position of one's body and its parts) and vestibular (balance) senses. They may be sensitive to air pressure, temperature and humidity. It may be very hard to combine two senses at once, such as looking at and listening to a companion, or watching and listening to TV or a DVD. Most have some form of synesthesia, the fascinating phenomenon in which stimulation of one sensory or cognitive pathway leads to automatic, involuntary experiences in a second sensory or cognitive pathway. For example, hearing a name or word may evoke a colour.

Our film shows two key sets of difficulties of life with severe Autism. Most obvious is the near-impossibility of communicating reliably with one's voice. Even if a person can utter sounds with his voice, these may not make clear sense to a casual listener. Others may assume that the person has no language or cognitive ability. The second set of problems is the extreme difficulty felt by many in co-ordinating and regulating the movements of all muscles and nerves and thus of getting one's body to do what the mind intends (including speaking).

HOLDING IN THE STORM

For many years, the behaviours of severe Autism were interpreted negatively, as deliberately obstructive and evidence of very low intelligence. But another way of understanding is to see that people are challenged by involuntary sensory and movement differences--in starting, stopping, executing, combining and/or switching actions, thoughts, emotions and speech. These neurological differences may also be called motor problems, inertia, sensory overload, apraxia, dyspraxia, echolalia, mutism, behavior disorder, catatonia or clumsiness. A. Donnellan, D. Hill, & M. Leary, Rethinking Autism: Implications of sensory and movement differences. **Disability Studies Quarterly**, 30, 1 (2010) http://www.dsq-sds.org/article/view/1060/1225

Movement differences affect the complex muscles and nerves that enable most people to speak. This is the most serious difficulty of living with severe Autism, partly because it is often misunderstood by other people. As Martha Leary explains, speaking involves "very complex cooperation among various systems of the body".

Consider the body systems involved: free movement of the jaw; agility of the tongue; well-coordinated, effective breath control; moving at the right time; coordinating the movements of these different systems; using facial expressions and gestures that match the meaning of what is said; using the vocal mechanism – 'voice box' or vocal folds – with the right

amount of force and pitch; keeping the rhythm of a conversation by taking a turn after your partner speaks, and so on.

This alternative view is supported by what the Bridges members say about their lives and challenges and is also reflected in the film.

Not being able to speak does not mean we have nothing to say!

Our lives are impeded by not controlling our movements. Being stuck in our bodies. I feel like I could explode. When I want to do something and am stuck, I feel helpless and sad but sort of resigned. When stuck, I usually show it by my hands clasped over my ears. I feel pain in my ears because it is emotionally taxing. Holding my hands over my ears gives me a feeling of control and some comfort. It keeps the storm in.

I feel that being stuck is the worst part of being autistic and it's what stops me from having a normal life. I get angry and want to lash out but I've learned to be patient and keep it inside.

I am always in motion because I feel restless. I can't stop moving because I feel movement inside my body. It is very hard to accept changes. I need help to get going because I get stuck and cannot move. I feel stuck and frustrated when I try to do things. I need help to get started and finish my action.

HOLDING IN THE STORM

People should know that it is always a struggle, even when there is no outward sign. We all lose it sometimes in different ways. I get hyper, run, scream and clap if it is bad.

I feel like that all the time. I would like to know what makes me so anxious and upset. I do not like it when I lose it but I cannot help it. It is hard to control myself and not know what it is about. It helps to be calm and not get angry with me and not to put me down.

When we need flexibility but don't have it, we get agitated. I am struggling with myself and how to be with others when I get upset. When people are hard on me, this makes it worse. I think they are being mad and severe in their judgments.

I have to struggle with my body every day. Most of the time now, I can keep things under control... But at other times, I have tailspins and go spinning downward. I mean losing my body's ability. I can't move. I am rigid. One of the worst things is feeling like my body is not part of me. I am seeing myself from outside and feel my thoughts are not from my head. I need to hold my hands over my ears to keep in control of my urges. My brain is rattled and jumbled like popcorn. I feel disoriented.

I can be very agitated. It is hard to communicate when our bodies are uptight I still try to type when I am stuck. I focus when I get started. I start to type and my ideas come to me.

What makes Matthew feel he is in a storm?

People living with Autism are potentially in stress all the time, experiencing a background noise of being out of sync with their surroundings and other people. Having to handle stimuli with two or more senses at once or having unexpected encounters may be too much. They may be "hyper" or "stuck". While it had been thought by some that Autism involves having too few connections in their brains and nervous systems, current theories suggest that people with Autism may be too over-connected and therefore liable to be overloaded by sensory stimuli from their environments.

Imagine combining pain and discomfort with inability to tell one's companions what feels wrong. No wonder there are sometimes meltdowns when the sensory overload becomes unbearable. A person driven to that extreme knows he is out of control but cannot help himself.

People whose families and carers have been understanding and supportive will try to "hold in the storm"—to contain all the explosive feelings by an effort of will. They may shut down to protect themselves but be unable to do this without getting stuck. Matthew does that. We see his stress only by very subtle signs.

HOLDING IN THE STORM

A stereotyped view of Autism is of loud and conspicuous behavior. You might ask: Why is Matthew so quiet and mild-mannered? In planning and composing this screenplay, it was decided not to depict the agitated and out-of-control behaviours that people may expect in any representation of Autism. Instead these are only inferred by some things that Matthew says and the "storm" in the film's title. The emphasis is on what he says with his "thought voice" which expresses his intelligence and intention to do his best. Rather than dwell on deficits and "what's wrong" our film suggests the potential.

How is Matthew able to hold in the storm?

Different people work out various ways. Hands clasped over ears represent both wanting to shut out unwelcome or confusing noises from the world and wanting to hold in the storm inside one's head and prevent it from boiling over. Someone who has been supported with understanding can devise unique ways to cope with sensory overload.

Escaping from noisy places to experience calm and beauty may be one way. It can help to have quiet spaces indoors with classical music playing and times of being alone. Or one can go outside to feel calmed by the wide open spaces and fresh air. Matthew and others find joy and peace in quiet spaces such as parklands and woods. Natural outdoor spaces, gardens of harmony and beauty, green landscapes, fresh air,

golden sunshine, moving water sparkling in the sun and interesting clouds all appeal to the visual and spiritual senses. The feeling of rhythm when riding in cars and especially trains can be soothing too. Some research is finding that people with ASD actually think more when quietly on their own than when with a group.

For people with Autism, the sensory overload of noise, bright lights, traffic, crowds, heat, stuffiness, or strong odours can quickly become unbearable. So can crowded places like malls, concerts, theatres or sports events.

Large family gatherings and special celebrations can be particularly hard. If it's important for social reasons to share in these times, it helps if a person is well prepared and feels free to take short breaks in quieter rooms. Taking a short break should not be interpreted as unwillingness to be with the group; the person usually returns after a few minutes. He is not necessarily trying to escape people but much prefers being with people individually or in small groups when those who understand his challenges can offer shared interests.

It helps to prepare ahead for stressful events and encounters. As one of Matthew's friends says "Surprise is my very worst enemy". Scripting and social stories can help. Matthew has been prepared to meet strangers on his walks, and to remain calm when asked if his dog may be patted.

HOLDING IN THE STORM

Matthew's "thought voice" and facial expressions

Why is Mathew's "thought voice" not matched by his facial expressions?

We should explain that the "thought voice" is a dramatic device developed for the purposes of this film. In real life, Matthew might take longer to feel, think and type words for his sensations of being outdoors and meeting a new person. He would likely need more time to recollect his sensations of the calm beauty of an early summer day in the park and near the river. He would probably express these later at home, in well-chosen words and metaphors.

There is indeed a mismatch between the eloquence of Matthew's words, as presented dramatically, and his inexpressive face. Sadly, this means that other people cannot perceive that Matthew really wants to be more social and to respond to friendly greetings. Matthew's brain does not easily make sense of visual information about other people, especially of their faces. While neurotypical people look for and find cues in the faces of their companions, people with ASD have great difficulty reading and understanding the facial expressions of others.

Why can't Matthew look Dave directly in the eyes? Not only do the eyes and brains of people with ASD not efficiently process details of the faces

of others. It's also likely that they may be over-stimulated by both seeing and hearing a new person, so they may shut out that information. They may recognize people in their lives more clearly by other aspects, such as their voices. So Matthew can recognize his friend and longtime neighbour, Geena, by her voice.

Lacking models from others, it is harder for adults with ASD to make their own faces express their positive feelings. As those with severe ASD often do not speak either, it is no wonder that neurotypical people may imagine that their greetings are unwelcome. It seems that Matthew and other adults with Autism lack interest in in other people and social situations.

But appearances may be deceiving. We know from what they tell us that adults with ASD like Matthew are very eager to get on with people and realize that, as for most of us, our quality of life depends on our relationships with our friends.

What you think you see is not all that's there. You might see me stop and think I don't want to do it. In reality my body is probably stuck or distracted. New people need to believe in me and be prepared to discover I may not be like they expect. If I sense they are paternalistic or patronizing, I will be distressed. Smiling is hard when people touch me if I don't expect it or I don't know them.

HOLDING IN THE STORM

How Matthew communicates

The film's last scene shows that Matthew can communicate though he does not speak. Some of us may be born without the capacity to speak; some acquire this handicap through illness or trauma. Some people with various reasons for muteness have been offered opportunities to use Augmentative and Alternative Communication (AAC) systems and aids. For more than 20 years, Matthew has been lucky to have access to both technology and the encouragement and support of experienced facilitators to type his thoughts and ideas. He is one of those who challenge the notions that only people who speak with their voices possess a capacity for language and communication and that being unable to speak indicates lack of intelligence.

Matthew uses a form of AAC known as Supported Typing. With an experienced facilitator stabilizing his body and typing arm, he can type on computerized devices with voice output that "speak" his words and record what he says. He has always wanted a device that speaks with "his" voice. During the past 22 years, he has used devices specially designed for people who cannot speak, such as the LightWriter designed by Toby Churchill. Laptops or desktops running WriteOutloud text-to-speech software are useful as they can speak and also keep a record of Matthew's quite long compositions. He now also uses an iPad for briefer interactions. Some communicators use lower tech aids.

More important than the devices are the attitudes of those who support Matthew and other communicators to talk by typing. They presume competence and make this clear to the people they support, thus providing valuable encouragement. With the right kinds of support, people with severe Autism or other movement differences can co-ordinate their movements better and type their thoughts and feelings in words that other people understand. The assistant provides backward pressure so the communicator can concentrate on reaching forward to touch or type on the device or simple letter board.

The form of support varies with each person and has been likened to learning to dance together. For some people, a touch on the shoulder may be enough. Others may need help in isolating the index finger with which they point to letters or press the keys. The amount of support needed may vary at different times, depending on state of health, level of anxiety, or distractions in the environment.

Some adults who cannot use their voices have changed their lives through discovering Supported Typing. Some develop independence in typing and continue in literacy and further education programs, and a few have graduated from college. Communicators who have been published include Sue Rubin, Lucy Blackman, Tito Mukhopadhyay, Larry Bissonnette, Alberto Frugone, Richard Attfield, Jamie Burke and Naoki Higashida. Several are featured in the film ***Wretches and Jabberers***.

HOLDING IN THE STORM

What we all yearn for: really good support to communicate....

Supported Typing is so liberating. I was locked before it. I had to hope others would see my intelligence in my eyes and behaviour, but these were not reliable. I saw that nobody really knew how smart I was. I had no way to express myself apart from some signs and pointing. People had to guess what I wanted and needed. It was so limiting. I was impeded by my movement disturbances. I might get things I needed, but couldn't say what I thought and felt.

I think other people saw a primitive childlike person who was not a thinker. I know it is hard to respect someone who paces and screeches, but says nothing intelligent. People did not know that I was trying to be in control of my body, when my body went in the opposite way from the way I wanted. I tried to keep calm, even though I got upset. People only saw my racing and pacing. Not my inner struggle, and that I was really working to hold in the storm. It felt like I was observing my own life but not controlling it.

When others did not understand me, I was sad and frustrated and agitated all the time. I got angry. I was hopeless: I never expected to find a better way. A few people really looked inside and past my Autism. Until Supported Typing I did not know I thought in words that others could understand; I was just absorbing their words. I was very surprised the first time I used ST. Now I had thoughts. Now I could talk.

An autistic poet?

Our film reveals that the poem "What it's like to be me", discussed by the college professor, was composed by a man with severe ASD who types to talk. How can we believe that?

What it's like to be me
AB, 29 Jan 2003
I'm a bundle of sensations
I get the urge
to touch and pick
and I must follow my urges.
Can you see my urges?
I can't tell you
I just show you.
I'm a bundle of nerves
and a jumble of thoughts.
I'm in constant motion
and my mind's always going.
I wonder what it's like to be you.
Do you wonder what it's like to be me?
I'm a time bomb waiting to explode
and a tear waiting to fall.

This poem is by Andrew Bloomfield who has typed his poetry since late 2002. He had more frequent communication support for nearly three years before that, using his chances to comment on his life and greatest needs. Just before his first poem, he met a music therapist who showed him that his words could be set to music. He learned to play some notes on guitar and piano while she sang the words.

Andrew has now published 140 poems in three collections: ***In my mind*** (2006), with his memoir ***Bridges over barriers in my life with autism*** (2011), and ***Images in my mind*** (2013). His thoughts and subjects have matured and include his passion for words and images. His poems are lyrical and rich in meaning and sustained metaphors. He gives us insight into how he experiences his life, rising above his severe challenges with hope, empathy and a hint of irony. Above all, he appeals for understanding and the chance to realize his potential and "to be me!"

Andrew's poetry is an example of the abilities of a fair proportion of people on the Autism spectrum. Some have remarkable analytical abilities in mathematics and science. Others are creative writers, musicians and artists. Factors in Andrew's poetry are his fascination with words; his need to grab our attention; his distinctive sensory perception including synesthesia that shows in his images; and the painful difficulty of picking out his messages, one character at a time, so he compresses his meaning into striking phrases and images.

MY LIFE WITH AUTISM

Bridges-Over-Barriers® by Andrew Bloomfield

In early January 2004, three men met in Guelph to share our thoughts, using what we now call Supported Typing. We found this time so precious that we have continued to meet almost every month (except in midwinter weather). More communicators have joined us, from all over southern Ontario, and we have members in New Mexico, Nova Scotia and France, as well as friends around the world.

Gatherings are planned in ways that help us all to stay calm. An agenda and questions are emailed in advance for discussions about anything from spirituality to special diets. A good structure is planned, with communication sessions morning and afternoon. Quiet music, a cool room, hikes and a lunch break are important. We may view and discuss videos on topics important to us and share our interests in music, painting, our experience of nature and plants, and our concerns about life transitions. Our parents, friends, facilitators and support workers bring us to Guelph and provide us with the physical and emotional support. They are patient and supportive; they believe in us and build our confidence.

We the communicators shape the flow of discussion and are the main talkers. We have grown close. It is exhilarating having a group of real friends, because we can really share and connect. We keep a record of what people say unless it is private. We type about our good news,

hopes and fears. There is always time to mention difficulties we may be having in our lives. We have talked about being autistic, obsessions and lack of control, and making friends. We prove that autistics can have feelings for others and stay focused for a long time. The ideas and words are ours. The gatherings are made by and for us; we have support and a safe environment to talk. Over lunch the facilitators and family members and supporters can add their thoughts and share news and resources.

Bridges-Over-Barriers became our name in mid-2005. A bridge was my image of how Supported Typing can connect my island to the mainland society and overcome my frustrations in being misunderstood and not in control of my life. Bridges is a very special support group. We are all quite different in our personalities and circumstances but very similar in how we communicate and see the world. We share what is important to us and always learn something interesting from the meetings. We all try very hard to be caring and respectful of one another.

Groups like ours are rare because we have been assumed not to have thoughts or feelings. We have not been educated or encouraged to express our thoughts. Once we are adults, people may think we have no hope of growing our minds and showing our intelligence. Bridges is special as we invite and welcome people to come to us; we cannot wait forever for the community to think of including us. Guests and

observers are welcome at Bridges gatherings: we ask them to come with open minds and to observe our "protocol". We need a calm quiet atmosphere to focus on thinking and typing. If observers come and make discouraging remarks without listening to us, this matters because we autistics have no filters, and so are bombarded by all kinds of stimuli through our senses including negative energy from others.

Guelph Services for the Autistic has helped Bridges to spread the word about communication rights and abilities. Individual communicators are supported to develop their skills and experience. In 2010 we published a documentary film with a book, ***In Our Own Words***. We have unbounded dreams of reaching everyone who needs support.

When I communicate with my Bridges group I feel like we've always been together and that we have a connection deeper than family. I guess we are in fact a type of family sharing the common bond of silence in a world that is seldom silent.

We have much to say. We support one another. We want our message to reach everyone who lives and works with autistic people. Please assume we are intelligent, help us to express ourselves, and listen....

Andrew Bloomfield. What everyone yearns for: The Ontario story of Bridges-Over-Barriers. ***Canadian Journal of Disability Studies*** 1, 2 (2012). http://cjds.uwaterloo.ca/index.php/cjds/article/view/46/53

HOLDING IN THE STORM

Community relationships: Awareness-> Understanding -> Acceptance -> Inclusion

In the past people who were different may have been hidden away. They and their parents are now encouraged to live and be seen in our communities. So we are all more aware of them—or we can be.

Here we address questions about Matthew that you may ask because you would like to get to know and be a friend of someone with ASD.

If Matthew is so severely affected by Autism that he can't speak, should he be out on his own?

Could someone who starts out friendly betray the trust of a person with ASD? Abuse of a vulnerable person is always a danger in our societies. Matthew has some protection against being abused in his own perceptions of other people and in the loyalty of his dog. While Matthew finds it hard to read people's facial expressions, he can sense the qualities of their characters. He would be unlikely to go off with someone he did not trust. His dog's loyalty and uniform are another protection. It's good that people in his neighbourhood and community know Matthew and his dog, are concerned for their well-being, and look out for them.

What is Matthew's dog supposed to do for him?

Matthew's dog is his great friend and companion, sensitive to his moods and needs, and closer to him for more of the time than any human being. He has natural qualities that have been well trained so he is aware of his master at all times. To reinforce this interdependency, Matthew cares for his dog—feeding him, letting him out into the garden, checking that his water bowl is always filled, preparing him for walks, grooming him, and expressing affection by patting.

His dog knows to follow Matthew and to stay with him at all times. When Matthew is stressed, he may lie under a weighted blanket with his dog lying on his feet and lower legs to ground him. When out walking, Matthew holds on to his dog's leash. They look out for each other. The dog almost never barks--only when he perceives some change in routine or possible danger to Matthew. People in Matthew's neighbourhood recognize him together with his dog and could raise an alert if man and dog became separated or seemed at risk.

Matthew calls his dog also his friendmaker-- and a bridge across the social gulf that separates Matthew from most other people. Given Matthew's lack of ease in relating to new people, this is a huge role. It's all right for his dog to be friendly with others, though it's best if others ask Matthew for his permission to pat his dog.

If Matthew can't speak, isn't he in danger of being misunderstood by the police? What happens if he can't give his name?

Matthew might be caught up in some mischief or even crime through no fault of his, just because he happened to be nearby. He could not speak his name if asked by the police and is therefore vulnerable. He might walk or even run away if accosted in a demanding tone. He does carry an ID card that he could present if given time. Being known in his community and the presence of his service dog could help.

Wouldn't it be better for Matthew to be in a group of other people with Autism or disabilities?

There can be service efficiencies in grouping people with similar disabilities and having staff on hand to supervise them. Matthew prefers to be himself in his daily life. For one thing, he is very sensitive to sounds and needs calm quiet spaces in his life. He has a strong sense of his individuality and wants his own home and good life that is designed for his abilities and interests. He wants to make his own choices. He is a mentor for others who live with ASD and feels a close bond with his Bridges friends. Like all of us, people like Matthew can enjoy and benefit from different circles of friendship and relationships.

Why isn't Matthew working at a job? People with disabilities should be doing some useful work.

Like most adults with Autism, Matthew does not have a regular paying job. There are various forms of work he has said he would like, in a library or providing a delivery service of flowers or prescriptions. He loves to garden and care for outdoor environments. Earlier in his life he worked at various menial tasks that have been devised for groups of people with limited abilities though the supply of work was often precarious and the experience was often boring or stressful.

Matthew volunteers in various ways, by copy-typing documents, collating mailouts and delivering public-interest flyers. He also contributes to society and his community of people with severe Autism by sharing his insights and experience in his books and poetry. He would like to increase his role as mentor for people who communicate differently and in training those who support adults with severe Autism.

Matthew welcomes the new opportunities that are being created for adults with ASD to use their "autism advantage" for paid work, such as those modelled on Specialisterne in Denmark to provide software testing, quality control and data entry services. Meticulon in Calgary recruits and trains people with "high-functioning" ASD and connects them with employers looking for hyper-focus and attention to detail.

There's someone in my neighbourhood who may be autistic. I'm wary of greeting him when we pass on the street. How can I do better?

When you don't know the person's name, start by saying Hi, Hello or Good day and smiling broadly. Then please wait several seconds (mentally count to ten) and you will probably get a smiling response or a Hi sound or sign. Next time, you might add some comment about the day's weather or a remark on what a fine dog he has (if he has one).

Once you get to know the person's name, including that in the greeting would be great. If the person has a human companion, you might express your interest in a brief conversation. If there is a dog and you feel inclined, you could ask if it's okay to pat the dog.

You may learn of a person's great interests and share them in a friendly way. He may be keen on running or gardening or may deliver the community paper. Friendly greetings from several people met locally help to build a stronger sense of community.

You might be interested in becoming a closer friend on the basis of shared interests, after a process of getting to know one another.

Take your time, slow down, don't rush the relationship!

Towards better lives and more secure futures

You might exclaim that life must be very hard for an adult who has severe symptoms of ASD. What is remarkable is how positively most think about their lives, especially if they have caring families and friends. Learning from experience, we propose this basic guide to a good life.

Start early and keep evolving these interrelated strategies, with and for each person. Independent Facilitation, a new service in many regions of Ontario, can help individuals and families to know about options and potential connections. Search online for a service near you.

1. Encourage self-expression and choices

- Start from earliest years with whatever ways work reliably, to communicate and be listened to, respected and understood.
- See the humanity, abilities and potential in each person, however severely challenged.
- "Listen" to understand each person's point of view and priorities.
- Observe and record what strategies work best.

2. Find and cherish friends of various personalities, ages and abilities

- Vulnerable adults need friends and allies in addition to family and paid workers. Friends get to know the person very well through shared interests and can support and continue the parents' roles. Friends support one another in a circle or support network.

- A natural and informal circle of support can be the basis for legally incorporating an Aroha entity, with core members as directors who have legal powers to supplement the role of parents and eventually succeed them.

3. Plan with the person

- Planning tools such as PATH (Planning Alternative Tomorrows with Hope), MAPS and CIRCLES, can help in working through transitions, envisioning a good life, and devising strategies to attain it.
- Such tools may be used by independent facilitators, a role that is now becoming more widely recognized.
- Two challenges are attending closely to the "voice" of the focus person and working out how to realize a plan.

4. Be creative and flexible in setting up key parts of the person's plan for a good life

- Don't be limited by the traditional service system. Consider what's really needed and find ways to make it happen. Understand the person's highest priorities and general goals. But also be open to the unexpected opportunities, even serendipity.
- Good surprises include new abilities and interests and unique gifts, or the appearance of wonderful new friends. Worsening health challenges or the disappearance of trusted support people or friends are harder. All need flexible responses and accommodations.

5. Daily activities must be real and fulfilling

- They need not be limited to paid work or group programs.
- They should include continued learning, healthful exercise and contributions to the community.
- Each person should have a way of life that is uniquely suited to needs and interests, and should be able to comment and make requests and suggestions.
- Support workers should be chosen by the focus person.
- Build components of a good life in stages that are right for the person. Try out various options, so person and all supporters have a basis for making choices. Build on transition supports that work.
- Strengthen Informal community supports that may be most lasting.
- People with complex needs may need completely individualized activities. Listen to what person says!

6. Consider the best kind of living situation for each person

- People need choices. Someone with hypersensitivities may need his own home, supported in the ways he needs and shared with companions he chooses.
- Practice alternate living experiences centred around the person as a basis for real choice of kind of home and living companions.
- Don't rush to buy a house or necessarily settle for some option based purely on what seems expedient for costs.

- Guelph Services for the Autistic (GSA) is dedicated to supporting individuals, with their families and friends, to develop and sustain good whole lives in homes of their own. GSA has pioneered an individualized model of home ownership that includes choice and self-direction by the person, long-term capital investment by the family, support circles (and Aroha entities), and recruitment and matching of lifesharers, supporters and volunteers. See ***Creating a Home and Good Life of My Own: the roles of a housing trust*** (Guelph, 2012).

7. A good life must be sustained, beyond the lives of parents

- Think ahead about how a good whole life is to be co-ordinated and kept going.

- An innovative mechanism is the Aroha, an incorporated entity of personal empowerment and support that can give trusted friends of the person and parents the legal powers to strengthen and continue family efforts. An Aroha can own property, and receive and manage resources to match person's needs and wishes. A good life can be grounded in friendships, shared activities and practice while the family is still around. GSA requires people and families wanting GSA support with its individualized model of home ownership to form an Aroha first.

- Advice on forming an Aroha is contained in several chapters of ***Creating a Home and Good Life of My Own: the roles of a housing trust*** (Guelph, 2012). Google "Aroha entities" to find online resources.

Learning more about Autism Spectrum Disorder

Along with the explosion in diagnoses of ASD since 2000, Autism information has exploded too, especially on the Internet. We need to take care in sifting it all to find what is reliable.

Fourteen years ago, we launched a pioneering website and Listserv from Guelph, to provide an information and communication service about adult Autism issues. At that time there were very few Internet resources about Autism. An Internet search for "Autism" in March 2000 found 134,000 hits while now there would be 16.7 million. Then there were virtually no Internet references to Autism in adults: now there are 238,000 including 14,000 published items in Google Scholar.

OAARSN: Ontario Adult Autism Research & Support Network still functions at http://www.ont-autism.uoguelph.ca though now shares its information roles with other sites. OAARSN represents a connection between the strategies that people and families have been pioneering since 1996 and all the big developments out there in Autism Spectrum Disorders and creative ways of supporting vulnerable adults. We continue to find it valuable to make connections between the particular details of individual lives and more general trends. We are dedicated to the interests of adults, especially those with quite severe Autism, encouraging whatever means of self-expression each person has, and supporting their families and friends.

The present OAARSN website is supplemented by monthly or more frequent news bulletins that also report research and announce events. You can be added to the Listserv for Adult Autism Issues or the Listserv for Creative Supports by sending a request with your full name and email address to ebloomfi@uoguelph.ca Membership is confidential.

For current research news, we recommend subscribing online to: **SFARI: Simons Foundation Autism Research Initiative**, launched in 2005. Its mission is to improve the diagnosis and treatment of autism spectrum disorders by funding innovative research of the highest quality and relevance, to benefit individuals challenged by these disorders. Visit https://sfari.org/

Top issues and most-viewed articles of 2013 included:

Broad spectrum of neurodevelopmental disorders
Gender differences in autism get their due
Long look at genes reveals surprise links to enzymes
Brain's garbage collectors get fresh look
Balancing signals of excitation and inhibition
Study of nonverbal autism must go beyond words
Long-term studies track how autism changes with age
Long neglected, severe cases of autism get some attention
Sense-jumbling synesthesia often accompanies autism
Autism brains are overly connected, studies find
Understanding contradictory connectivity reports in autism

Anxiety, autism may share common basis
People with milder forms of autism struggle as adults

Hundreds of books and articles are published each year relating to Autism Spectrum Disorder.

The world's leading publisher of Autism titles is **Jessica Kingsley Publishing** at http://www.jkp.com/

Parentbooks at http://www.parentbooks.ca/ in downtown Toronto offers the largest selection of ASD books for sale in Ontario.

In our region, the **Kitchener Public Library Autism Collection**, funded by **Waterloo-Wellington Autism Services** since 2002, contains about 1,000 current books, videos etc. Items may be borrowed by people from outside the region on special cards and also through Inter-Library Loan. Link: http://www.kpl.org/ref/healthlink/autism.html#top

Brock University's New Archive on ASD, started in 2013, is collecting the day-to-day records of people living or working with ASD in order to preserve the wide-ranging history of autism in North America.
See more at: http://brocku.ca/library/collections/special-collections-archives/autism-collection

ASD services and links in Ontario and our region

Most cities and regions have some organization or group concerned for children and youth with Autism. Adults may not be as well served.

Autism Ontario, leading source of information and referral, has 24 regional chapters. http://www.autismontario.com

Kerry's Place Autism Services, Canada's largest service provider for ASD, offers services in several Ontario regions. http://www.kerrysplace.org

The Redpath Centre in Toronto specializes in people of all ages with Aspergers Disorder http://www.redpathcentre.ca/

Regular conferences are organized by **The Geneva Centre for Autism** and **Woodview Mental Health and Autism Services;** and **Autism Canada Foundation** and **Autism Intervention Clinic of Guelph** (mainly on biomedical aspects),

Autism Spectrum Connection In our region offers resources and communication tools http://www.autismspectrumconnection.com/

Waterloo Wellington Autism Services sustains the Autism Collection at the Kitchener Public Library. http://www.kpl.org/ref/healthlink/autism.html

Guelph Services for the Autistic is a housing trust that also sponsors initiatives such as this film, Aroha entities and Bridges-Over-Barriers®. Search OAARSN website: http://www.ont-autism.uoguelph.ca/

More Questions

Our film will evoke many more questions such as these:

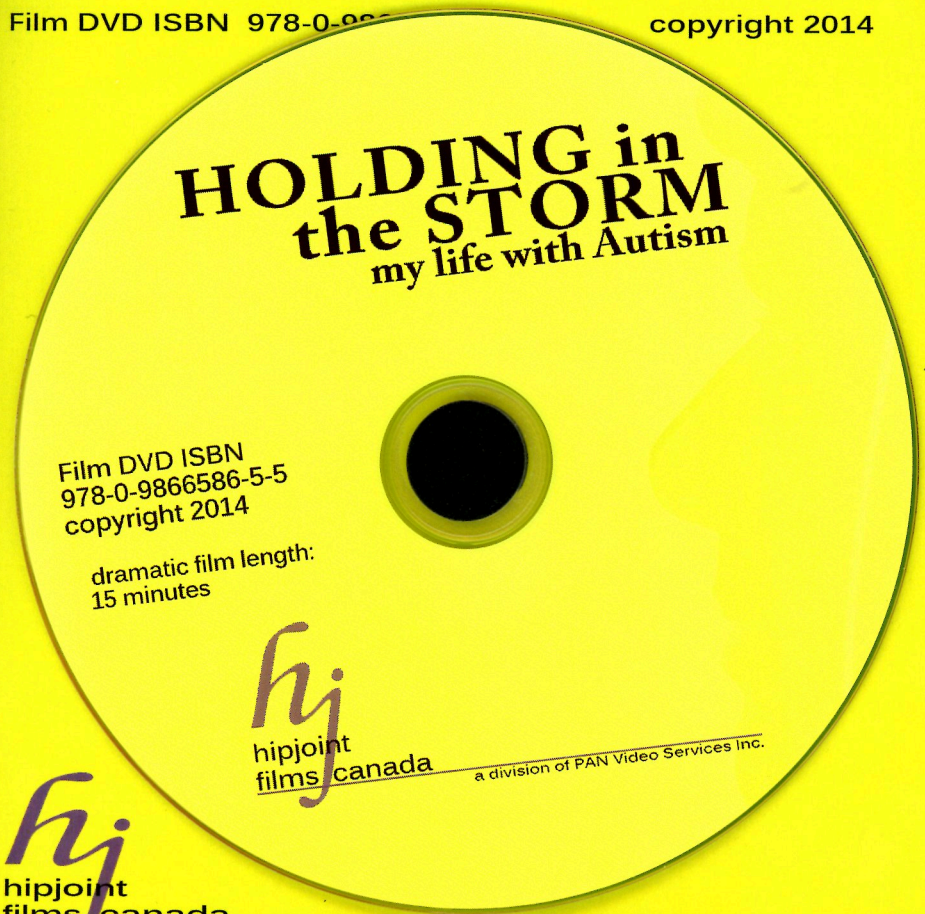
- What impressed me most in this film? Do I identify with the key characters Matthew, Dave, Geena or Professor McCord?
- This film speaks to me. How can I learn more about respectful ways of including adults with ASD in my community?
- I'd like to get to know someone with Autism as a friend. I'd feel more comfortable doing this in a small group. Is this possible?
- Someone we know may have undiagnosed ASD. Should we suggest trying to get help?
- Why did you make a dramatic film with actors rather than a documentary of real people living with ASD?
- What does the title "Holding in the Storm" mean to me?

The **Holding in the Storm blog** will maintain discussion of issues raised by this film: http://holdinginthestorm.blogspot.ca

Some groups are planning to show our film in gatherings in their communities as a basis for discussing how to build community and enrich lives through friendships and shared interests.

To request copies of the film on DVD with Discussion Guide, or to ask questions, please email ebloomfi@uoguelph.ca Basic cost of DVD plus book is $10 plus postage etc if required.

Film DVD ISBN 978-0-98
copyright 2014



hipjoint
films canada
a division of PAN Video Services Inc.

The film **HOLDING in the STORM** © takes place both in a park and a university lecture theatre. Our main character Matthew has severe Autism and is unable to communicate with his voice. He expresses himself through his 'thought voice'. We feel the visible and at times invisible social barrier this creates, as he's approached by another character, Dave. We get a sense of Matthew's witty and intelligent character; we feel his happiness, sadness and frustration. All this reveals the many layers of his complex life. A university professor uses a poem to challenge his students to discuss its meaning and intent, and in the end reveals the poet's identity.

Produced by: Christine Zorn and Deirdre Lindsay
hipjoint films canada, a division of PAN Video Services Inc.

The discussion guide is offered as an aid to reflect on the meanings of the film, and to stimulate ideas of how people with Autism Spectrum Disorder (or other differences) can be better included in our communities. We have imagined questions that the film may suggest to viewers. The guide provides some answers to what it's like to be an adult with Autism.

We hope you will continue to think and ask questions about the film. Join our blog discussions at http://holdinginthestorm.blogspot.ca.

Discussion Guide ISBN 978-0-9866586-6-2